

**The Legislative Blue Ribbon Commission on Autism
Task Force on Early Identification & Intervention
Tuesday, November 14, 2006**

Attachment C

Agenda Item III: Roundtable Discussion on Policies & Issues

- **Early Identification By Pediatricians**
 - Time Constraints
 - Lack of Tools (training/testing instruments)
 - Diagnosis often made by clinical assessment only.
 - Have screening completed before the visit so that the outcome can be addressed at the beginning.
 - Closing the loop with specialists, making referrals and getting that information back before the visit.
 - HIPPA
 - Posters in a waiting room for developmental milestones leading parent to their regional center.
 - Standard 800 number needed.
 - Post in preschools, child care center (anywhere where children/parents are).
 - STOPPING—"Let's wait and see."
 - Lack of knowledge –education on the entire spectrum (What autism is?)
 - Systems of care in community based referrals.
 - Symptoms to look for and awareness of the increase in diagnosis, has not reached a consensus—first need to agree there is a problem.
 - Pediatricians and Child Psychiatry have not had an autism rotation.
 - Continuing education seminars.
 - Pediatricians do not always have the experience and comfort level with ASD.
- What is the standard for pediatricians? What is their role in the diagnosis process? (Not responsible for a comprehensive screening process).
 - Medical and Educational consult necessary
 - Barriers of reimbursement present a problem.
 - Children on medi-cal need to be identified.
 - Parents are hesitant to go to the doctor when they see early warning signs because they are afraid to get the diagnosis which leads to a delay in early intervention.
- Screenings should be offered at preschools, day care centers, so that 50% of children are no longer missed. This initiative has already been put in place in some areas but should be widespread.
 - Multiple settings using predictive tools.

IIC_Summary of Issues & Barriers (Second Meeting)

- Standards, requirements, funding.
 - All child care workers to be trained on early warning signs, developmental milestones.
- Waiting lists...children left on a list waiting for screening. Once diagnosed often have to wait for therapists/services, wait on regional centers.
 - Shortage of resources both man power and funding.
- System of Triage needs to be created.
 - Standards of diagnosis are not used (gold standards)—need consistency and implementation of best practices.
 - Universal screenings, referral, and services should be linked. Currently this is not how things are.
 - Child care is an untapped resource of people who could be used for screening.
- Children in underprivileged/underserved communities are being diagnosed 2-3 years later than those in more wealthy communities.
 - What are the frontlines of defense for these communities?
 - Parental knowledge, resources.
 - Lack of healthcare.
 - Do not get proper medical attention.
 - Seizure disorders, hearing, gastrointestinal ect.(co-morbid medical issues).
 - Cultural awareness, language barriers.
 - Misdiagnosis.
- Developmental screening could be created and be a more effective tool for pediatricians.
 - Start a dialogue about what is being seen and what should be looked for.
- Power of early intervention—getting the knowledge out about the impact of early intervention and intervention to reduce the wait.
- State needs to find a way to pay non-medical providers to do screenings.
- How are we defining best practice?
- **Awareness---** goes before early intervention.
 - Quality public information.
 - Early warning signs.
 - Parental rights.
 - Autism is a spectrum disorder and there are many types out there.
 - Community awareness- tear down the stigma of ASD.
 - Go to where parents are...churches, shopping centers, union halls, ect.
 - Quality scientific information.
 - Neuroplasticity- Increasing awareness of science on early intervention
 - Ideal time for diagnosis.
 - Data—screening outcomes—present to government for funding (cost benefit).
 - Developmental milestone awareness.

IIC_Summary of Issues & Barriers (Second Meeting)

- Language, motor skills, appropriate age-level play.
- Transition from regional center to educational setting is not fluid.
 - Resources are not always put into place and there is time lost and the child/family is left in limbo.
 - Interagency agreements.
 - System reform.
 - Money wasted on lawyers, experts, ect. while family is fighting to get services
 - Parents need knowledge of the system—know that reimbursement is available for particular services and testing (German Berero on phone).
- **Intervention**
 - Inconsistency in quality of care—way by which to hold accountability for quality and competency of those providing services.
 - Development of training for professionals and paraprofessionals.
 - Reimbursement rates.
- Fragmented System
 - Transition from IFSP to IEP—“Johnson case”—difficulty in maintaining services.
 - 21 regional centers to 1000 school districts...no consistency in vendors is forcing discontinuity of care.
- Professionals lack reinforcement and staff training and development and leave the school system/agency—low retention rates.
- Wage inequality between pre-k services and middle secondary educational services breeds low retention for professionals.
- Positive behavioral support system within schools.
- Periods of presumptive eligibility—keep system seamless to family so they never lose services.
- Enforce quality standards and monitor progress over time. Age Appropriate best practices in education need to be enforced.
 - Special education continues to be grossly under funded.
- Teacher training—provide a class on autism—train teachers how to write measurable goals.
 - Paraprofessionals.
- Problems with new standards for teacher credentialing in CA is creating a lack of resources.
- Access to resources and intervention in certain communities.
 - Families that may rely on public transportation are too far away from available services.
- Utilization of knowledge among professionals.
- Professional development should be an ongoing process for professionals and general education teachers, perhaps as often as once a month.
 - Reinforcement.
 - Leverage in UC system—interns utilized for services.
 - Childcare provider training.

IIC_Summary of Issues & Barriers (Second Meeting)

- CalWorks obstacles placed on parents, need follow through and accuracy for exemptions for parents of children with Autism.
- Relationship between the parent and service systems—prevents us from creating services that are strength based.
 - Parents do not want to say anything positive about progress because they do not want to have services yanked.
- Lack of agreement in interpretation of best practices—difference in the amount of hours of services among school systems/providers. (10 vs. 40).
 - Quality of professional and services.
 - Credentialing.
 - Providing evidence based recommendation—take what we know right now and create a best practices/standards to be implemented.
 - Fragmentation in intervention models.
 - Educate on what these models are.
 - Programs are only as good as the person implementing the program.
- When approaching legislature (things to keep in mind):
 - The more expensive something is the less likely it is to get done.
 - Where consensus exists is a good place to start, you will receive less opposition.